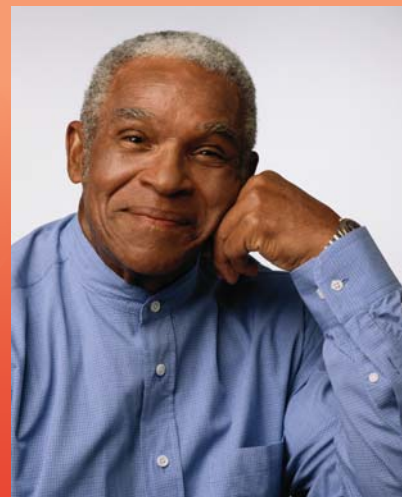


The Needs of the Sickle Cell Population in Missouri

Focus Group Report



Missouri Department of Health and Senior Services



Missouri Department of Health and Senior Services

Bureau of Genetics and Healthy Childhood

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Focus Groups on the Needs of the Sickle Cell Population in Missouri

Background

Sickle cell disease is an inherited blood disorder that causes red blood cells to function abnormally, by becoming rigid and curving into a sickle-like shape. This makes it difficult for the cell to pass through tiny blood vessels, resulting in painful blockages that prevent the flow of oxygen throughout the body. Individuals with sickle cell disease may experience many complications including severe pain, anemia, increased risk of infections, kidney and lung damage, and stroke.

Individuals with sickle cell disease require the care of an experienced team of health care providers. Techniques for managing sickle cell disease include the careful use of medication to treat pain, frequent blood studies to monitor oxygenation and transfusions. While some pain episodes can be treated at home, others require emergency room care and hospitalization. Preventive health measures, such as immunizations, prophylactic use of penicillin, nutritional education, physical therapy, genetic counseling, social/financial services, and psychosocial support can also help ease the difficulties associated with sickle cell disease.

Sickle cell disease affects about 1/400 Blacks/African Americans in Missouri and 1/12 has sickle cell trait, the carrier state of the disease. The target population primarily resides in the two metropolitan areas, Kansas City and St. Louis, Central Missouri and the southeast part of the state.

It is important to obtain and learn from the perspective of those living with sickle cell disease in order to better understand and determine what best meets their needs. In general, those living with the disease, as well as their family members, are willing to share their challenges in accessing medical care and personal experiences that are unique to persons with the disease. The focus groups provided an opportunity to express their opinions regarding the specific service needs that are important to them.

Purpose

The objectives of the Sickle Cell Standing Committee in organizing the focus groups was to assess the impact of sickle cell disease on communities in Missouri, examine existing services and resources addressing the needs of individuals with sickle cell disease, and develop recommendations to address the problems.

Process and Methodology

Understanding the needs and challenges of individuals living with sickle cell disease is significant in implementing statewide sickle cell programs and services. This is an important objective of the Sickle Cell Standing Committee in assuring that programs and services are responsive to the needs of the target population. A workgroup was formed during the March 2012 standing committee meeting to implement an awareness activity to support this objective. A brief literature review was conducted to establish the basic structure for a focus group. The workgroup developed a demographic questionnaire to gather information on the individuals represented in the focus group, and a set of questions was developed with input from the standing committee members. There were six questions selected as the discussion guide for the

focus groups. A timeframe of 60 to 90 minutes was to be allowed for the group discussion, depending on the number of participants and how the discussion progressed. The goal was to invite 15 to 20 participants with the expectation that 8-10 would agree to take part in the focus group.

For each focus group location, invitations to participate were first by phone or personal contact and then a follow-up with a letter to confirm the date, time and location was sent to each invited participant to confirm participation. The recruitment process used was that the individual would have sickle cell disease, was a parent/caregiver of an individual with the disease, or had a direct connection to the sickle cell community. No incentives were offered.

Three focus groups were conducted around the state with individuals/families living with sickle cell disease through the collaborative efforts of the Sickle Cell Standing Committee, the hemoglobinopathy resource centers (Truman Medical Center in Kansas City and University of Missouri in Columbia), the St. Louis Sickle Cell Association, and Missouri Department of Health and Senior Services, Bureau of Genetics and Healthy Childhood. The first focus group was held in Kansas City in October 2012, a second focus group was arranged in February 2014 in St. Louis, and the third focus group convened in Columbia in June 2015.

Participant Information

Each participant was asked to complete a questionnaire prior to the discussion session. Overall, 15 people participated in the three focus groups and through the questionnaires the following information was collected:

Age Range: 20 – 85

Gender: 73% Female, 27% Male Race: 93% Black/African American, 7% Other

Education: 7% Less than high school, 20% High School, 33% Some College, 40% 4 year degree or higher

Employment: 46% Employed, 13% Seeking Employment, 7% Retired, 7% Self employed, 7% Student, 20% Other (not working, disabled, homemaker)

Income: 13% less than \$10,000, 33% \$10,000-20,000, 7% \$20,000-30,000, 33% \$50,000 and up, 13% No response

Medical Coverage: 14% Medicaid, 26% Medicare, 40% Private Insurance, 14% Medicaid and Medicare, 7% Private Insurance and Medicare

Do you think there is enough public awareness about sickle cell disease? 0% Yes 100% No

Have you ever experienced depression or anxiety as a result of your sickle cell disease?
53% Yes 27% No 20% No Response

Do you feel that you are being labeled as a “drug seeker” when requesting pain medication for your sickle cell pain? 27% Yes 46 % No 27% No Response

Have you ever experienced discrimination as a result of having sickle cell disease?
If “Yes” how? 47% Yes 47% No 6% No Response

- Employers are not sure they want to hire you because of sickle cell disease, or once you are employed and inform employer that you have a chronic illness and then are hospitalized or ill, attitudes change even if your illness does not affect your job performance.”
- “I was asked (by both security and the doctor) why I passed three hospitals to be at the one that was treating me.”
- “I was not paid attention to when I placed the call light on because it was not time for pain meds (I wanted something different).”
- “The nurse taking a long time to bring pain medications and telling me that screaming was not going to help my pain. I should just relax and patiently wait”.

Do you think that most health care providers are knowledgeable about the treatment of sickle cell disease? 13 %Yes 80 %No 7% Somewhat

Discussion Results

The following questions were used as the discussion guide for the focus groups.

1. What would you like to be doing in one-five years from now?
2. What tools will you need to accomplish this?
3. What is the major health care need that you feel is not being met for you?
4. How do you feel your health care needs have changed over the last 3-5 years?
5. What types of problems have you experienced in trying to get health care?
6. What additional resources do you feel need to be available for people living with sickle cell disease?

Each focus group used the same set of questions to guide the discussion session for the group. The discussion was started with questions to engage each participant. Overall participants were eager in responding about their personal goals and had high expectations for their lives. Many of the needs identified were related to the negative stereotypes associated with the disease and increasing education for health care providers. These responses emphasize the need to continue to develop programs and services to eliminate these issues. The common themes and needs identified from each of the focus group sessions are summarized in the table below:

Kansas City Focus Group October 19, 2012	St. Louis Focus Group February 14, 2014	Columbia Focus Group June 27, 2015
<p>Improving the emergency room (ER) experience with shorter wait times and care that is specific to each person's history</p> <p>Increasing patient education in the area of pain management without the use of opioids</p> <p>Increasing patient education about sickle cell complications and the transition from pediatric to adult care</p> <p>Increasing public awareness of sickle cell disease (SCD) and sickle cell trait (SCT)</p> <p>More programs and educational literature for adults with SCD</p> <p>Education for health care providers on sickle cell particularly as it relates to overcoming the negative stereotype that people with sickle cell pain encounter</p> <p>Addressing feeling of isolation caused by the disease and desire to be treated like people who do not have SCD</p>	<p>Doctors and nurses in the ER lack training in pain management</p> <p>ER doesn't treat SCD patients well</p> <p>Individual care - everyone is put into the same care plan ("One size fits all" approach to SCD treatment)</p> <p>Increase awareness in schools and the general public</p> <p>Programs to encourage sickle cell disease patients to take charge of their care from a young age</p> <p>Support system in schools</p> <p>Doctors to encourage patients to be more involved in their care</p>	<p>Additional resources, facilities, and funding for testing</p> <p>Alternative medications</p> <p>Better training of primary care providers (PCP) in the area of SCD</p> <p>Increased public awareness of SCD</p> <p>Advocate for; implement more statewide outreach</p> <p>Additional resources for education of patients, families, and PCPs</p> <p>Better linkages with existing community resources</p> <p>Lack of support groups</p> <p>Lack of trained ER personnel in the area of sickle cell disease</p> <p>Lack of transportation for children and families</p>

Recommendations

The recommendations for programs and services to address the findings of the focus groups include the following:

- Outreach to the pediatric and adolescent sickle cell disease population to provide resources to advocate for themselves from an earlier age;
- Programming for school systems to support children with sickle cell disease;

- Educational programs developed for schools to educate students about sickle cell conditions;
- In-service programs for physicians and nurses to increase understanding about sickle cell disease; and
- Education initiatives to increase awareness of sickle cell disease and sickle cell trait among the general public.

Plans to Address Needs

Education and awareness about sickle cell disease and sickle cell trait was a need identified in all of the focus group sessions. The Bureau of Genetics and Healthy Childhood will work with the St. Louis Sickle Cell Association to promote sickle cell trait awareness in the St. Louis metropolitan area.

